

Paliative Care: A Global Duty

PALYATİF BAKIM: KÜRESEL BİR SORUMLULUK

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Summary

For patients nearing the end of life, pain and suffering decreases their well being and diminishes their interactions with loved ones. Palliative medicine is invaluable to a patients recovery and/or to ensur their peaceful death. In the developed world, palliative care can be cost effective. In less developed nations, it can be made affordable and sustainable. Ethical principles require us to believe what patients tell us about their pain, and to alleviate it when possible. This paper discusses the global value of palliative medicine, and examines factors that hinder its provision. Much suffering in both developed and developing countries results from trauma, accidents, illness, and the process of dying. In many settings, the duties to heal, comfort, and alleviate suffering require professionals to challenge and advocate change in the standard end-of-life care practices accepted within the system in which they work.

Key Words: Pain management, End-of-life, Palliative care, Hospice, Professional duty

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Özet

Yaşamın sonuna yaklaşan hastalar için acı ve ızdırap, mutluluklarını azaltır ve sevdikleriyle etkileşimlerini eksiltir. Palyatif tıp, hastaların iyileşmesinde ve/veya huzurlu ölümlerinin sağlanmasında çok önemlidir. Gelişmiş dünyada palyatif bakım pahalıya mal olabilir. Az gelişmiş uluslarda maliyeti düşürecek ve sonuna kadar aynı kaliteyle sürdürülecek hale getirilebilir. Etik ilkeler, hastaların ağrıları hakkında ne söylerlerse inanmamızı ve mümkün olduğunca ağrıyı azaltmamızı gerektirir. Bu makale, palyatif tıbbın global değerini tartışır ve koşullarını engelleyen faktörleri inceler. Acı, hem gelişmiş, hem de gelişmekte olan ülkelerde travma, kaza, hastalık ve ölüm sürecinden kaynaklanır. Birçok ortamda, iyileştirme, konfor ve acıyı azaltmaya karşı sorumluluk, çalıştıkları sistem içinde kabul edilen yaşam sonu bakım standardında değişime meydan okuma ve desteklemekte profesyonelliği gerektirir.

Anahtar Kelimeler: Ağrı yönetimi, Yaşamın sonu, Palyatif bakım, Hospis, Profesyonel sorumluluk

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The relief of suffering is a traditional goal of the medical profession that is still a priority today (1). More people are living longer due to medical and technological advances, but much of their longevity comes at the cost of suffering imposed by chronic illness or disability. Such suffering may take physical, spiritual, emotional, social, and financial forms. Palliative care uses a holistic, multidisciplinary approach to assist patients with chronic and terminal disease by relieving their suffering and improving their well being.

In Britain, palliative care is practiced in all major hospitals by teams that include specialist physicians, nurses, and others. There are national standards of practice for palliative care that are

maintained and reviewed regularly at each hospital. There are pharmaceutical guidelines for different kinds of suffering including bone pain, neuropathic pain, vomiting, breathlessness, muscle spasm, and convulsions. The British guidelines also distinguish between treatments for other forms of suffering like anxiety, depression, confusion, and terminal restlessness and anguish (2).

In the United States, the American Medical Association (AMA) recently began to offer a training program for physicians on how to improve end of life care. This program involves workshops, videotapes, and computer-based exercises (3). It makes treatment recommendations for the varied symptoms that can occur with chronic or terminal

disease and during the last hours of living, including pain, anxiety, and delirium. Concern about the quality of life for those living with serious illness is apparent in the AMA's attempts to better educate physicians about pharmaceutical aspects of pain management and other end of life issues. Recent books geared to help both doctors and patients validate this concern (4,5).

With or without aggressive life saving therapies, the process of dying may last for days or weeks, and typically involves suffering that can and ought to be alleviated. This paper argues that doctors, nurses, and other health professionals have a duty to advocate and practice palliative care.

What is Palliative Care?

The hallmarks of palliative care are honesty about dealing with the reality of dying and death, commitment to assessing the total comfort needs of patients and their close family or friends, and the will to address these needs with a multidisciplinary approach involving a team of other professionals (6). Palliative care has been described as a philosophy, from which stem goals and clinical interventions to assist dying patients. Interventions involve symptom management (through medications and specialties like anesthesia, surgery, radiotherapy, and psychiatry). Psychosocial interventions are equally important. There are

“...conceptualized as the type of care that would be offered by a nurse, doctor, social worker, chaplain, and “ordinary caring person” all rolled into one. The team approach is thus vital, since no one professional can offer all these types of care at the same time. ...There is also a concern with the practical aspects of terminal care, both for the patient and for the patients' home carers. This can include advice on financial matters (state benefits as well as personal finances), equipment and aids to facilitate home nursing tasks, co-ordination with other sources of statutory and voluntary support (community nurses, volunteers to help with shopping or transport), as well as 24-hour general advice line (6).”

The Need for Palliative Care

A study of over 9000 elderly and seriously ill patients found that pain is commonplace and troubling among them (7). During the last 3 days of life many patients suffered from moderate to extremely severe pain and/or severe dyspnea at least half of the time (7). About 25% of them had severe confusion, one in eight had severe nausea, and 73% found it difficult to tolerate their physical symptoms (7). Pain was also a primary concern for dialysis patients, patients with HIV, and elderly residents of a long term care facility (8). Qualitative methods were used to identify and describe the concerns these patients had about their end-of-life care; these included avoiding inappropriate prolongation of dying, achieving a sense of control, relieving their burden, and strengthening relationships with loved ones (8). Aggressive palliative medicine is necessary to address these concerns because patients will not be able to feel a sense of control, relieved of burden, or able to strengthen their relationship until their pain and anxiety is alleviated. Pain management is an essential component of quality end-of-life care.

Hospice is one approach to palliative medicine. Hospice care involves a team approach to provide pain relief, symptom management, and psychological support. It can be provided in a hospital unit, at home, or in institutions called “hospice” that are dedicated solely to care of the dying. Typically, patients are accepted to hospice care if their physician predicts that they have six months or less to live. Advance care planning is helpful but relies on doctors to sensitively communicate with patients about each patients preferences for care while they are still able to express their wishes. Hospice and advance care planning help to relieve the burden on patients, families, and professionals working in end-of-life care. A series of documentaries broadcast in the U.S. by the Public Broadcasting Service (PBS) illustrated the benefit to patients and carers of hospice, and that hospice can be cost effective (9).

Cost Effectiveness

As the field of palliative care has expanded, much money has been allocated to improve it

around the world (6). As a result, there is increased demand for evaluation of palliative care services to ensure that these meet existing needs, that patient preferences are considered, and to assess the efficacy of new forms of therapy (6). More research is needed to confirm the effectiveness of palliative care in relieving suffering and reducing costs.

Anecdotal accounts describe the value and effectiveness of palliative care, but quantifying such data is challenging. Strategies to provide such data tend to be qualitative, but may include experimental methods, surveys, case studies, and naturalistic observations (6). Targets for assessment include patients, carers, institutions, services, and financial records. The cost effectiveness of palliative medicine, as well as its benefits to patients and families, must be documented if it is to be continued or expanded.

A review of existing data on end-of-life care shows that pain management is an effective cost-saving strategy (10). One study found that the use of parenteral analgesics reduced both days in hospital and overall cost per patient (10). Another found that other forms of pain management reduced both hospital admissions and expenditures (10). When comparing hospice to conventional care during the last six months of life there was a financial saving to patients of 17%, and during the last one month of life the savings for hospice patients was 47% (10). This savings would also benefit providers and governments that subsidize healthcare.

Global Issues

The cost effectiveness of palliative care in countries with high tech facilities is increasingly clear, but what about less developed nations where high tech care is not affordable or available? Do such countries need palliative medicine or hospice, and would the cost of such care fall within their per capita expenditure on healthcare? Many deaths in developing countries are due to diseases like cancer and heart disease, and these patients suffer the same symptoms as patients elsewhere. Much of the related pain can be managed with oral medication, which is the least expensive form of

pain control (10). In at least some developing nations, aggressive pain management would be affordable, sustainable, and relieve much suffering. Non-economic factors, however, also hinder the delivery of palliative medicine.

Non-economic factors

Cancer prevalence is increasing in less developed nations, where it is particularly difficult to obtain medical access to opioid analgesics (11) because regulatory measures block access (12). The WHO Conventions on Narcotic Drugs and on Psychotropic Substances aim to ensure availability of controlled drugs for medical use, while preventing their diversion for abuse. However, overly restrictive regulations impede availability and result in unnecessary suffering, particularly among cancer patients (who often present initially with advanced disease, because poverty hinders access to healthcare) (13). Much of their suffering could be alleviated with analgesics, other therapies, and institutional policies that would cost little and could be sustainable in less developed nations.

In societies and cultures that are less economically developed, people tend to have a fatalistic mentality founded in cultural and religious influences (14). Such influences result in a history of unwillingness to challenge authority (14). In developing countries, a fatalistic approach to illness and death leaves patients resigned to suffering. They often turn to religion as their only source of comfort. In the Caribbean, a moderately developed region of many independent nations, anecdotal accounts attest to the pain of dying patients and the solace they seek in religion. Such accounts led to the founding of one of few, if any, hospice facilities in the region (by a physician/ethicist in Jamaica who obtained funding through private donors). When interviewed, several relatives of recently deceased patients in Grenada also report that their loved one suffered severe pain while dying but did not receive (sometimes could not afford) pain medication. In spite of much suffering, there is no demand for change or improvement because socio-cultural conditions perpetuate the fatalistic perspective.

Even in developed nations, there is limited access to palliative care. Globally, obstacles to palliative services include lack of education among leaders of healthcare programs, governments, and universities, and limited education among health professionals about palliative medicine and pain management (12). Many health professionals and administrators are not taught the distinction between drug tolerance and addiction with respect to opioids and other pain medications. Patients with serious or chronic pain become tolerant to increasing doses of opioids, but do not become addicted, even if doses are increased (3,4). Most physicians and nurses do not know basic rules about pain management: that pain is as bad as the patient says it is, and that there is no usual dose and no maximum dose for medication (3,4). When patients report feeling more pain after a steady dose of opioid has been effective for them, the dose should be increased by at least 50% (4). When pain returns as the drug wears off (end of dose failure) the time between doses should be decreased, or the dose should be increased (4). Moreover, when pain diminishes due to recovery, patients are easily weaned off medications by slowly decreasing the dose (4).

Increasing access to palliative care begins with education and awareness. Governmental restrictions on narcotic and psychotropic drugs need to be altered to make medical access easier, and governmental and institutional policies are needed regarding use of resources and delivery of services. Equally important, health professionals must overcome taboos about drug use and addiction. Organizational steps toward providing palliative care services include 1) recruiting and training full time specialists; 2) developing simple patient assessment and management guidelines that are locally compatible; 3) educating government and healthcare professionals about the need for such services; 4) implementing the 1-2-3 component described below; and 5) monitoring for quality control (12). The 1-2-3 component provides direct (tertiary) care to the most distressed patients, and consultation service to primary care physicians (secondary care). It has increased

patient access in developing and developed countries that have a “strong family physician/generalist tradition”, like Britain, Canada, and Chile (12).

Professional Duty

Pain is more than just hurting. It decreases ones physical, emotional, social, and spiritual well being. It causes people feel lethargic and/or nauseous, lose their appetite, sleep badly, and function poorly (4). Pain causes people to experience less enjoyment, more anxiety and/or depression, and makes them unable to concentrate on anything except their pain (4). People suffering from pain feel a loss of control, have less interaction with friends, and are less able to enjoy sex or affection; they may have a changed appearance, and feel that they are a burden to loved ones (4). Pain medications are invaluable to a patients recovery and/or to ensuring their peaceful death. Although treatment sometimes has side effects like constipation, confusion, and drowsiness, these are less severe than the pain itself (3,4).

The ethical principle of respect for persons requires us to believe what patients tell us about their pain, and to watch for other cues to tell us how bad it is. Medical beneficence supports palliative medicine because it is in a patients interest to make them feel better. Physicians and other health professionals have a duty to comfort as well as heal, and to alleviate pain when possible, even when this requires controlled drugs. Unfortunately there are taboos about the medical use of such drugs, which are confounded by a fundamental ambivalence about the place of death in human life. Callahan questions why it is so hard for doctors to talk with patients about their illness and end of life wishes (15). He suggests that doctors need incentives to work toward understanding the culture of healthcare institutions, to see how that culture can be made more user friendly, and to stimulate dialog about the meaning and place of death in human life (15).

The duties to heal, comfort, and alleviate suffering are found in all traditions of medicine

and nursing. Sometimes fulfilling this duty requires professionals to challenge the status quo. There is virtue in having the courage to voice concern, even as a means of starting dialog and raising awareness. Drawing attention to failure of health policy, institutions, or individual actions to provide palliative care and to manage pain effectively is a professional duty. Doing so may prevent future patients (and ourselves when we become patients) from suffering needlessly.

There is much suffering in both developed and developing countries which results from trauma, accidents, illness, and the process of dying. Medicine and nursing attempt to heal, but that alone is not enough. They must also alleviate suffering during recovery, and/or at the end of life. When they can't treat, heal, or save the life of someone with chronic or terminal illness, health professionals have a duty to offer comfort in every way possible, holding their hand, listening, providing clinical and psychosocial interventions, and trying to improve the healthcare system in which they work.

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